



Let's Talk: Clinical Trial Readiness & Community Preparation

Speaker: Luke Rosen, KIF1A.ORG

August 17, 2019

Visit <u>kif1a.org/2019Conference</u> to watch a recording of this presentation.



Our role in R&D



What is R&D?

Research & Development

WE ARE THE "AND" IN R&D



R

Columbia University DEPARTMENT OF PEDIATRICS

College of Physicians and Surgeons



And other KIF1A researchers / Collaborators





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Who's going to step up?

Biotech / Industry?

Individuals?

Translational Researchers?



How we Accelerate R&D: Our Jobs

Be proactive with your data and your story: *Trust the Foundation. Trust the Chung Lab.*

Be active in the rare disease community: Remember, being present is active.

Be contactable: We can't expect urgency if we don't respond with urgency.

Take video: What matters most? If we can't capture it, we can't fix it.

Get Zoom: We're global. We're strong. We can meet real-time. One mission, one foundation.

Be relentless: In your love for our children, for our community, for our science and for yourself.



Weekly Jobs: Every week we'll email you a job

Our Job Next Week

- Email every biotech with a neuroscience program and tell them we need their help today. Challenge them to "think rare." The science and technology exists.
- Monday each KIF1A family will receive a list of email addresses and contact information for every biotech and an example message.